

# A Cancer Journey

Greater Newcastle Cluster



Colin Wightman  
Dreaming - The Dragonfly



Health  
Hunter New England  
Local Health District





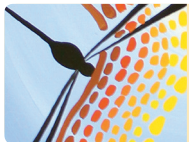
# Wontakalowa Yuri

Greeting Awabakal language - Welcome Aboriginal people

Hunter New England Health District would like to acknowledge the original custodians of this land and pay our respects to the Elders both past, present and future for they hold the memories, the traditions, the culture and hopes of Aboriginal Australia.

**WARNING:** This booklet may contain images of, or have references to, deceased people. There may also be words or descriptions that could be culturally sensitive. This could upset some Aboriginal and Torres Strait Islander people; however HNELHD and Cancer Network wishes no disrespect or distress to Aboriginal and Torres Strait Islander people, families and community.

**All images are displayed with consent.**



**Turool** to be in a state of healing



# Your Cancer Journey

## Kamilaroi Man - Matthew Taylor's Story



My name is Matthew Taylor. I was diagnosed with cancer during my HSC year in early January 2013. I woke up in immense pain and went to my mother who took me directly to the hospital. Within in few hours I'd had an ultrasound, CAT scan & blood tests which confirmed I had stage 2 cancer. The next few months were full on. I had

urgent surgery to remove the cancer one week after diagnosis. I then proceeded to have a PET scan at The Calvary Hospital in Newcastle. The staff there were great. Being 17, I meet the wonderful staff of the Youth Cancer Service who were there to help myself, my mum & sister. We had regular check-ups to see how we were coping and they put us in contact with Redkite who gave us assistance when needed.

As a young person with cancer I became a member of CanTeen Australia who are great support throughout my cancer journey. I got to meet other young people affected by cancer, others who really understood how I was feeling. I am currently on the Leadership committee of CanTeen for the Hunter and Northern Division.

I am 12 months post treatment. I still have regular blood tests & scans to check the cancer hasn't returned. I have now completed my HSC & am currently studying a Bachelor of Science at the University of New South Wales.

If I had not told my mother & kept this to myself my outcome could have been very different.

### Matthew's message

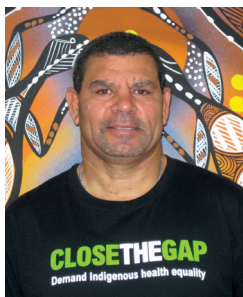
Early detection don't be shamed to talk to someone. Cancer doesn't discriminate and it doesn't get only the old people.

I'm young and I had Cancer.



# Foreword

Tony Martin - Director of Aboriginal Health



This Cancer Journey Booklet has been produced to improve the effectiveness of Aboriginal peoples journey through the system for those that are

affected by cancer related illnesses who are located across the Hunter communities. Firstly I would like to acknowledge and thank our brothers and sisters and their families that have shared with us your individual insights from an Aboriginal perspective. Opening up these types of conversations with others assists in reinforcing the importance of health education and screening from an Aboriginal perspective. The Hunter New England (HNE) Cancer Network is committed to improving access to cancer prevention, screening and treatment

services for Aboriginal people, in an effort to “Close the Gap” in health and well-being between Aboriginal and non-Aboriginal people. The benefits of the collaboration will be relationship building and trust which will have a flow on effect improving cultural respect, awareness and sensitivity.

We want to empower Aboriginal people to collaborate with mainstream partners in the provision of advice, planning, service issues and identification of resources where appropriate in meeting the needs of the Aboriginal population relating to cancer illness.

We want to support Aboriginal people diagnosed with cancer as they progress through their cancer journey, linking them with cancer services in the acute sector and services available in the community more generally. Ongoing work will continue that

will enable us to:

- Reduce risks
- Identify culturally appropriate strategies that work in consultation with Aboriginal people and communities
- Improve cancer literacy through education and yarning
- Improve our data quality to effectively monitor progress and improve cancer care delivery for our people

I hope you find this resource useful and encourage you to share the contents with family and friends.

HNELHD Cancer Network encourages you to provide feedback about your cancer journey and how we can improve your experience through email [HNECancerNetwork@hnehealth.nsw.gov.au](mailto:HNECancerNetwork@hnehealth.nsw.gov.au)



# Foreword

Dr Tony Proietto - Director of Cancer Services and Cancer Network



This Cancer Journey Booklet has been produced to help Aboriginal people affected by cancer, their families, friends and communities throughout the Hunter New England region.

Cancer prevention, screening and treatment is the core responsibility of the Hunter New England (HNE) Cancer Network. It is well known that there is a significant discrepancy in cancer outcomes between Aboriginal and non-Aboriginal people.

The Cancer Network is committed to improving access to cancer prevention, screening and treatment services for Aboriginal people as part of the “Close the Gap” strategy. We need to work together to build a relationship based on trust, cultural awareness and sensitivity. It is essential that Aboriginal communities and health services collaborate to ensure mainstream services are able to meet the needs of the Aboriginal population who are affected by cancer.

We want to support Aboriginal people diagnosed with cancer through their journey, linking them with cancer services in the treatment centres and services available in the community more generally.

Ultimately we want to have a cancer service that works in consultation with Aboriginal people to develop culturally appropriate strategies that will improve cancer care for Aboriginal people and communities. In engaging with the cancer service you may be asked for some information about yourself. Any information you give will be used to improve the service to Aboriginal people and help provide a more positive experience.

I hope this booklet will help patients and families dealing with cancer and help to Close the Gap.

# Awabakal Nation

Calvary Mater Newcastle is located on the traditional lands of the **Awabakal Nation**. You are welcome to bring your family or friends with you on your journey.

**Yarning** is very important when you find out you have Cancer – to listen – not only to your health care team but also your family.

For all of your cancer treatment you will be given dates and times for your appointments. You will be given access to people who can support you along the way including an Aboriginal Hospital Liaison

Officer and a Social Worker. Don't be afraid to ask to see one of these people and ask any questions that you have.

You will be given an appointment card with the dates and times for your treatment and next clinic visit.

**Senior Aboriginal Health Education Officer**  
**Phone: 02 4985 0386 Mobile: 0408 017 184**



**Piriraal Yuri** meaning standing strong Aboriginal people



Kathryn Bensley AHLO



# How to find Oncology - Calvary Mater Newcastle

Edith Street, Waratah, NSW 2298

**Car Parking** There is a drop off area in Platt Street & main entrance.

There is multi-level car park in Platt Street which is \$4.00 per day to park – Car Park 1 (P1)

For Radiation treatment there is a free car park. You just drive up to boom gate and swipe in.





# Calvary Mater Newcastle Hospital

Corner of Edith Street & Platt Streets, Waratah, NSW 2298 Phone: 02 4921 1211



Radiation Treatment Car Park (Swipe card access only)



Platt St \$4/day to park - Car Park 1 (P1)



Edith Street Entrance



Platt Street Entrance



# Medical Oncology

The Medical Centre is located on level three of the new clinical services building (known as south block) and is the main centre for all outpatient appointments.

**Medical Oncology** – Your Doctor will yarn to you about tests and treatments with you. You get to talk to your doctor about the best treatment for you.

Medical Clinics are conducted Monday to Friday

- Notify the reception staff of your arrival
- Very important to identify as Aboriginal or Torres Strait Islander
- You will see a Doctor who specialises in Cancer
- There will be a specialist Cancer Nurse or Coordinator who will help you
- You can ask for the Aboriginal Health Worker who will support you and your family.

**Phone 02 4985 0386.**

Appointments/Reception ..... Ph: 02 4014 3195

Aboriginal Health Worker ..... Ph: 02 4985 0386

Bookings Office ..... Ph: 02 4014 3190

Clinic Nurses ..... Ph: 02 4014 3190

Cancer Care Coordinators ..... Ph: 02 4014 4751

Breast Care Nurse ..... Ph: 02 4014 4752



# Haematology Services

Clinics Monday to Friday Phone: 02 4921 1211

- Notify the reception staff of your arrival
- Very important to identify as Aboriginal or Torres Strait Islander
- You will see a Doctor who specialises in Cancer or a nurse practitioner
- There will be a specialist Cancer Nurse or Coordinator who will help you
- Ask for an Aboriginal Hospital Liaison Officer who will support you and your family

**Senior Aboriginal Health Educator - Phone: 02 4985 0386**

**Social Worker - Phone: 02 4014 4811**



**Marai Kikiliko** meaning wellbeing



You see the Doctor at the Medical Clinic



# Day Treatment Centre

Chemotherapy Treatments Phone: 02 4921 1141

- Notify the reception staff of your arrival
- Very important to identify as Aboriginal or Torres Strait Islander
- You will see a Doctor who specialises in Cancer or a nurse practitioner
- There will be a specialist Cancer Nurse or Coordinator who will help you
- Ask for an Aboriginal Health Worker who will support you and your family



# Radiation Oncologists

**Yarn** to your Radiation Oncologists.

You will see a specialist Doctor for your Radiation treatment, this is a Radiation Oncologist.

Bring along your family for support and if you need an Aboriginal Health Worker phone: 0407 438 684

The Doctor will yarn to you about tests and treatments and advise you of the best way to treat your cancer.

You may need a combination of treatments of Chemotherapy and Radiation it's called **combined therapy**.

**Chemotherapy** is a medicine given to treat cancer by infusion or needle or can be tablet form.

Ask questions and write the answers down, don't be afraid a family member can do this:

- How long does the treatment last?
- How many times do I have to come back?
- Report back to the front desk just in case you need to see someone else



Radiation waiting area



**Malang Yuri** meaning together Aboriginal people



# Radiation Planning & Education

Phone: 02 4014 3125 Booking Clerk: 02 4014 3611 or 02 4014 3612

**Radiation planning and education will be provided by your Radiation Therapist.**

Yarn to your Radiation Therapist (RT), they will give you advice on looking after your self during treatment

- Notify reception staff of your arrival
- Very important to identify as Aboriginal or Torres Strait Islander
- Can take up to 1-2 hours and is painless
- You will have a CT scan
- RT will give you a small dot tattoo
- RT will give you your next appointment

time and phone number should you have any questions

- Nurse will see you after this session before you leave

Next step is planning the process, which you don't need to attend

- All information, scans etc. gathered RT's will create your own specific treatment plan
- Treatment can not start until your plan is finalised by your Radiation Oncologist Doctor



# Radiation Treatment

Phone: 02 4014 3125 Booking Clerk: 02 4014 3611 or 02 4014 3612

## The machine that delivers radiotherapy treatment is called a Linear Accelerator

- Notify the reception staff of your arrival
- Most patients have treatment daily Monday to Friday
- Depending on your Cancer treatments may take between 1 day to 9 weeks, your Doctor will tell you how many
- You may need treatment 2 times a day, in the morning and the afternoon
- The time on the treatment bed is only a few minutes
- The machine will make a buzzing noise, you won't feel a thing
- You may need to change into a gown
- Very important that you stay very still, remember to talk to RT's and nursing staff
- The RT's will be outside but can talk to you through a video
- **REMEMBER** always see the receptionist when leaving just in case you need to see someone else





# Travel & Accommodation

## Isolated Patients Travel and Accommodation Assistance Scheme - IPTAAS

If you need to travel more than 100kms in any week for treatment or if you need assistance contact the Aboriginal Hospital Liaison Officer.

You can get financial assistance with your Travel and accommodation costs through the IPTAAS scheme.

**A family member or a carer can stay with you**

### **If you need assistance contact:**

Aboriginal Hospital Liaison Officer -  
02 4985 0386 or 0408 017 184  
or the Social Worker - 02 4014 4804

### **Patient & Carer Accommodation:**

02 4014 3950 or 02 4014 3952



McAuley Lodge



Villa Units



McAuley Lodge



Villa Units

# Your Support Circle

## Your Treatment Team Health Professional

General Practitioner (GP) Name:	Phone:	Your local doctor who provides ongoing care. They will be able to help other doctors understand your cancer journey.
Social Worker Name:	Phone:	Provides support, Counselling, Referral, Financial support (Centre link), Travel assistance and accommodation
Aboriginal Hospital Liaison Officer Name:	Phone:	Is Aboriginal. Can offer support to you and your family. Talk with other members of your treatment team.

## Your Support Circle

### Some other Health professionals you may meet:

- Physiotherapist
- Occupational therapist
- Pharmacist
- Dietitian
- Radiologist
- Pathologists
- Administration (Front Line Clerical)



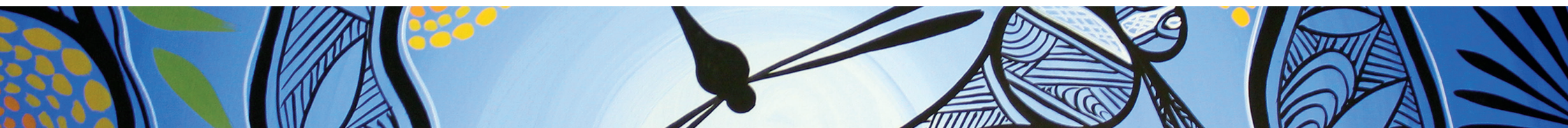


## Your Treatment Team Health Professional

Cancer Coordinator Name:	Phone:	A specialist Nurse, knowledge of cancer, supports you and your family through your cancer journey
Surgeon Name:	Phone:	Doctor who performs operations.
Radiation Oncologist Name:	Phone:	Specialist in Radiotherapy treatments.
Medical Oncologist Name:	Phone:	Specialists in Chemotherapy and treatments.

## Your Support Circle

If you are at home and require emergency treatment ring 000 and ask for an Ambulance



# Speak Up



Asking questions is a good way to learn about your Cancer - **Have a Yarn**  
You may not always understand what is going on or what is said.  
You can get help from your - **Support Circle**

Here is some example of questions that might help you:

- You can ask any doctor, nurse or worker to write down what you have been told. So that you can read it later or don't forget
- Can I have a copy of my pathology (Blood results, test results) and can you explain it to me?
- Can you explain my treatment?
- What type of cancer it is?
- Who can I speak to about my feelings?
- Can I get help with travel and accommodation?
- Who is my Social Worker?
- Who is the Aboriginal worker and can I meet them?

**Write your own questions here:**

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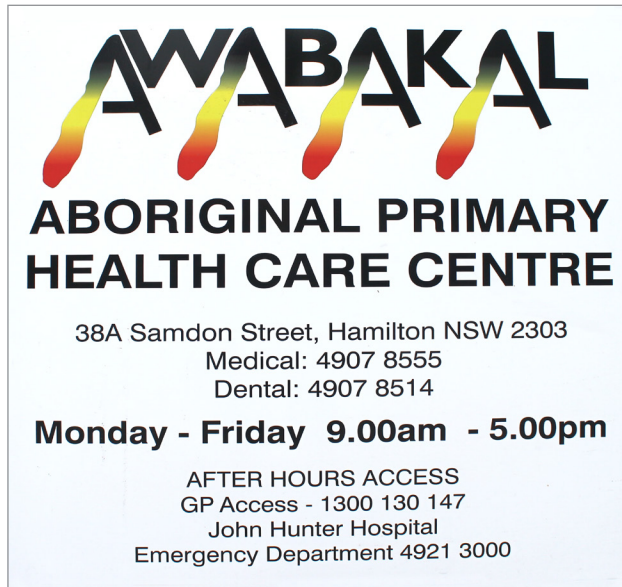


# My Follow Up

## After Cancer Care - Get Checked Up

When you have finished your treatment, it is **important to have regular check-ups** with your local doctor or your oncologist.

- Your doctors will tell you how often they would like to see you.
- You can also ask for information on what type of treatment you had and your results.
- If you or your family have any questions, you can ask your local doctor or oncologist.



**Awabakal Aboriginal Primary Health Care Centre**

Phone: 02 4907 8555

# Helpful Information

There are other support services outside of the hospital that can also assist:

## The Cancer Council Help line

Free Legal Service .....13 11 20

Free Wills .....13 11 20

## Medicare Local

Helpline .....1800 652 800

.....02 49 252 259

## Salvation Army

Salvo Care Line .....1300 363 622

## The Leukaemia Foundation

Helpline .....1800 620 420

Monday to Friday 9am - 5pm

## Department of Human Services

Centre Link and Medicare for  
Aboriginal or Torres Strait Islander people

Helpline .....1800 136 380

Carers .....132 717

Financial Information .....132 300

## Look Good Feel Better

Womens business

Phone .....(02) 9837 3434

Fax .....(02) 9837 3435

Email .....nsw\_act@lgfb.org.au

Monday - Thursday

## Hunter Prostate Cancer Alliance

Helpline .....1300 881 826

.....02 4968 9455



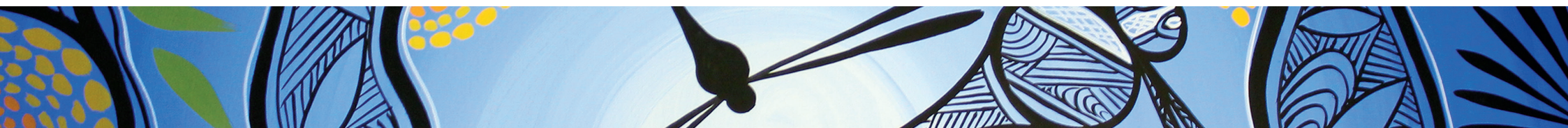


# Acknowledgements

**The Cancer Journey Booklet** working party would like to acknowledge Aboriginal communities of the Hunter, Dr Anthony Proietto, Jill Lack and Tony Martin for your initial concept for a culturally safe booklet for Aboriginal people diagnosed with cancer in Hunter New England Health.

This initiative was partly funded by the Cancer Institute NSW, HNE Cancer Network and the Aboriginal Health Unit. The Cancer Journey Booklet Working Party is grateful for the help and assistance provided by Calvary Mater Newcastle Oncology staff.

Be aware the spelling for names of Aboriginal groups may differ. Unless otherwise referenced, the spelling of Aboriginal language names in this booklet are taken from the NSW Aboriginal Lands Council Map. This map is just one representation of other map sources that are available for describing Aboriginal Australia. The map indicates only the general location of larger groupings of people which may include smaller groups such as clans, dialects or individual languages in a group. The boundaries are not intended to be exact and the spelling of each language Nation is variable.





# Acknowledgements continued

## Would like to acknowledge the input from

- Artist Colin Wightman - The Dragonfly
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- Mid North Coast Local Health District (A Cancer Journey Booklet)
- Kathryn Bensley - Aboriginal Health Worker Calvary Mater Newcastle
- Dr Anthony Proietto - Director of Cancer Services HNELHD
- Brendon Cutmore - Aboriginal Health Unit HNELHD
- Tony Martin - Director of Aboriginal Health HNELHD
- Oncology Team Calvary Mater Newcastle
- Jill Lack - System Innovation Manager HNELHD Cancer Network
- Jacqui Allen - Miromaa Aboriginal Language Centre
- Ingrid Airlie - Public Affairs & Communication Manager Calvary Mater Newcastle
- Lyn O'Brien - Acting Director Clinical Services Nursing, Calvary Mater Newcastle

## Steering Committee Cancer Project

- Dr Anthony Proietto
- Tony Martin
- Sue Arber
- Karen Dahdah
- Jill Lack
- Michelle Wilkes
- Brendon Cutmore
- Rose Wadwell



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# Acknowledgement of Art Work

## Colin Wightman Dreaming – The Dragonfly

This story is about how dragonfly came to be.

There was once a group of children, both girls and boys, and like all children, they were free spirited and happy go lucky, they would do things and go places forbidden by their parents.

One boy in the group would always tell on them and get them into trouble because he wanted to be the show off, the most important in the group by being the one noticed by all.

One day the group decided that they would no longer be betrayed by this boy and they managed to get him changed into the dragonfly.

The groups were much happier without the boy who as a dragonfly still flies around bringing messages about seasons and good things.

The dragonfly still likes to show off its colours and its beauty as it soars through the air allowing the light to glisten off its body and fragile wings.

Everyone notices the dragonfly because of its beauty and ability to fly. Focusing on the dragonfly positive qualities rather than focusing on the negative, allows one to see beauty, feel positive and be happy.

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